# CHARGE Accounts

Summer 2005 A Quarterly Newsletter for Families and Friends Vol. 15 No. 2

CHARGE Syndrome:
CHARGE has four
major features -
Coloboma, Choanal atresia,
Cranial nerve abnormalities, and
Characteristic ears
More information on website

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*Thank You!*

**Thank You!**

*Thank You!*

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Thank You!

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*Thank You!*

**Thank You!**

*Thank you Bruce Appell for all your work on the Board of Directors from 1997 to 2005 and as President of the Foundation from 1999 to 2005.*

**Thank You!**

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**Thank You!**

Thank You!

Thank You!

## In this Issue . . .

### YOUR HELP IS NEEDED!

Please share your stories, parent tips, questions, book reviews and suggestions for other features you would like to see included. Remember this is your newsletter!

# FOUNDATION ACCOUNT

## PRESIDENT'S NOTE

**Bruce Appell**

Hello Everyone,

Only a few weeks left until many of us will be enjoying one another's company in Florida. Thanks to all who have and will continue to devote many hours to ensuring that each of us has a wonderful time during the conference.

As many of you know my term as President will be ending at the conference in Miami. I have served on the Board for the past eight years and as President for the last six years. After much thought and consideration, I have decided to vacate my position on the Board in order to spend more time with my family. I would like to thank Marion for her dedication to the Foundation and her hard work especially during my term as President. I would also like to thank those who have served on the Executive Committee during each of my terms as President. Each member of the past and current Boards are very special to me and I have enjoyed working with each of you. Our job as a Board has not always been easy but we have worked together to overcome obstacles in order to assist the Foundation to grow to new heights. I wish the new Board and the newly elected Officers the best of luck in the coming years.

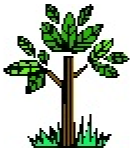
I would also like to thank Tommy and Robin Adkins, the Greater Waldorf Jaycees, and the Maryland Jaycees for their support and fundraising efforts. Without their support and substantial funding, the Foundation could not have accomplished many of the goals which have been achieved due to their efforts. I cannot thank each and every individual for their support as I would like to for I know I would surely leave a name out. Please know that from the bottom of my heart I thank each of you for your support and hard work.

A special thanks to Uncle Kenny and Aunt Cheryl Moretz for their efforts and dedication to Uncle Kenny's corner during the International Conferences but also during other functions such as the Mid-Atlantic CHARGE Syndrome Conference and the Maryland Deafblind Family Weekend. All of these functions have benefitted our children with CHARGE as well as their siblings.

Susan, Ashley, Abby and Jessie will not be attending this year's conference as far as we know at this time. Ashley has the opportunity to assist the Coordinator of a Field Hockey and Lacrosse Camp. The Coordinator of the camp is also the Head Women's Lacrosse and Field Hockey Coach for the college that Ashley is hoping to attend and play both lacrosse and field hockey for. We felt that Ashley could not miss this opportunity. The girls as well as Jessie are disappointed that they will be missing out on the Miami trip. Hopefully they will be able to attend the 2007 conference.

Finally, I have a very huge thank you to Susan, Ashley and Abby for all of their support during my time on the Board and as President of the Foundation. I was fortunate to have the support of three very wonderful women. I may have been President but there were many times that I discussed issues and obtained their opinions concerning the foundation. There were nights away from home, late night phone calls, and plenty of e-mails for the Foundation that needed my attention forcing them to take on many other tasks for our family. I truly can not thank them enough for supporting me over the past eight years. Susan, Ashley, and Abby I love you very much and thank you.

**Thank you, everyone,**
**Bruce**



## EXECUTIVE DIRECTOR'S NOTE

**Marion Norbury**

**CHARGE Syndrome Awareness Week** is July 17-23. It is your opportunity to spread the word about CHARGE Syndrome to the media and your public officials, schools and other organizations in your area. You can distribute brochures to your library, clinics, newspapers, tv and radio stations, write a short description of CHARGE Syndrome and promote the Foundation and the Conference in July or use the news release inserted with this newsletter.

**The 7th International CHARGE Syndrome Conference** is almost here. The keynote speakers will be Conny van Ravenswaaij, M.D., PhD. from The Netherlands, Belinda Arnell from Australia, and David Brown from California.

If you can't attend the conference, the Fall Issue of CHARGE Accounts will have a wrap-up of what went on.

* * *

### Committee Chairs

Conference – Neal Stanger
Research – Meg Hefner
Fundraising – Brownie Shott
Education/Outreach – Jim Thelin

**All board members have a special email address:**
**(firstname)@chargesyndrome.org**

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# FOUNDATION ACCOUNT

## CONFERENCE COMMITTEE

The Conference Committee for the CHARGE Syndrome Foundation is solely responsible for the biennial conference held in July of all odd numbered years. The committee is broken down into numerous subcommittees including childcare, volunteer recruitment, programming and agenda, fundraising and local host. Members of this committee will be asked to be available for email discussions and, as we get close to conference time, may also be asked to spearhead different projects. Anybody interested in joining the committee should contact Neal Stanger during the conference or by email (neal@chargesyndrome.org) to get a more comprehensive plan of what is involved. We will also be having a lunch-time meeting during the upcoming conference on Saturday July 23rd for anybody who plans on working towards the 2007 conference. More information on this will be available when you arrive in Miami.

Neal Stanger, Conference Chair, neal@chargesyndrome.org

## EDUCATION AND OUTREACH (E/O) COMMITTEE

The E/O Committee was created last year in the re-organization of the committee structure of the Foundation Board. The Vice President was selected as chair and four other board members of the Board as committee members. The purpose of the committee was to consolidate a variety of activities and house them in a single committee. These activities include the following:

-Public relations
-Website
-Newsletter
-Educational materials
-Alliances with other organizations
-Membership
-Advocacy

Many of these activities were already being conducted, but this committee was created to coordinate all of the efforts. The ultimate goals of the committee are to be able to provide information to the membership and the public at large, to facilitate interactions with professional organizations that have similar interests, and to develop educational materials on the substantial body of knowledge on CHARGE syndrome that has been developed by professionals and parents. The Foundation has reached a point of maturation where the services provided by the E/O committee are needed to inform groups about the work of the Foundation.

In this year of transition and convention planning, the E/O committee was not active. Business and activities were handled by particular individuals and not through the committee. Next year, however, the committee will become active and begin its work. If you are interested in joining this committee, contact:

Jim Thelin, E/O Committee Chair, jim@chargesyndrome.org

## RESEARCH COMMITTEE

The Research Committee does all of their business by email. The most frequent thing we do is review proposals from potential researchers who want access to Foundation members for a study. Past examples include Kim Blake's study of adolescents and scoliosis and the Baylor gene-identification study. We never give out our mailing list. However, if we feel a study is worthwhile, confidential, and safe, we ask the researchers to provide information, envelopes, and postage and we mail the information to the appropriate population. Each family can then decide whether or not to participate. The Research Committee will be the "first pass" in deciding about participation in such a study. The Board of Directors has the final say on participation or non-participation. In several instances, committee members have provided valuable input which resulted in slight changes in the questions asked or other aspects of the research projects. Occasionally, researchers request funding to assist with their studies. In these cases, the Research Committee makes a recommendation to the Board regarding funding from the Research budget.

Currently, the committee consists of a dozen or so members. Most are parents, but many of those also have professional expertise. It is particularly important to have the parent members, so we can be sure the studies are appropriate to our membership and respectful of individuals with CHARGE and their families. If you are interested in being on this committee, please send me an email and/or sign up in Miami.

Meg Hefner, Research Committee Chair, meg@chargesyndrome.org

## PROFESSIONAL ADVISORY BOARD (PAB)

The PAB is a subgroup under the Foundation's Research Committee. The PAB is composed of more than 40 professionals and parents from around the world who have an interest in CHARGE. Many of the professionals are those who are the speakers at the CHARGE conferences. If you look at the conference program you will see the large number of disciplines represented. The PAB meets the afternoon before each International CHARGE Syndrome Conference to share ideas about the research that is being done and the knowledge that has been gained over the preceding two years.

Last year, the members of the PAB produced a special issue of the *American Journal of Medical Genetics* on CHARGE syndrome under the editorship of Tim Hartshorne, Meg Hefner (Research Committee Chair), and Sandra Davenport. It was an extraordinary collaboration that resulted in an outstanding collection of research on the behavior phenotype in CHARGE. At the 2005 meeting, the PAB will have the first opportunity to discuss the findings of the investigators from the Netherlands on the mutations of the gene CDH7 in individuals with CHARGE syndrome. This is the first evidence of genetic etiology for CHARGE syndrome. It will be an exciting meeting.

Over the years, a great deal of information has been obtained by surveys of parents of children with CHARGE. However, participation is often time consuming because of the preliminary diagnostic and descriptive information that must be obtained. At the 2005 conference, a proposal will be made to develop a central data base that would allow parents of children with CHARGE and individuals with CHARGE to enter background information one time and then participate in subsequent studies without having to re-enter the large amounts of information that is necessary for valid research. The PAB will be asked to determine if it is possible for the Foundation to establish such a database that meets the strict requirements for confidentiality and for the protection of the rights of research participants.

Jim Thelin, PAB Chair, jim@chargesyndrome.org

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## CHARGE Syndrome in the American Journal of Medical Genetics

**Meg Hefner, M.S.**

The last two years have been very exciting for CHARGE. In 2003, the first Behavior Symposium was held at the Cleveland CHARGE Syndrome Conference. In 2004, the first major gene for CHARGE syndrome was reported. And in 2005, a special issue of the American Journal of Medical Genetics devoted entirely to CHARGE Syndrome was published. It is available from the Foundation for purchase. It may be found also at a medical library.

For many years, the medical community and the CHARGE Foundation conferences focused primarily on the medical and developmental aspects of CHARGE. Thanks to the efforts of Tim Hartshorne (psychologist and father of a young man with CHARGE), behavior in CHARGE has become a major field of study. Tim organized the Behavior Symposium and asked each presenter to send us a written summary of their research and presentation. We received about a dozen articles. Tim, Sandra Davenport and I edited those articles and submitted them as a group to the American Journal of Medical Genetics. The editors of the journal were delighted to have such a comprehensive look at behavior in a genetic syndrome. They accepted all of the articles, including one written by three parents. In addition, the Journal had received a number of other submissions about CHARGE. They decided to dedicate an entire issue of the Journal to CHARGE Syndrome. The March 15, 2005 issue of the journal is a Special Issue on CHARGE syndrome. These articles are also available to you and the professionals who work with your children. Please keep in mind that they are written for medical and educational professionals – some translation may be needed!

**Purchase entire journal**: The Foundation has a limited number of the entire issue of the journal available for purchase at $20 each (postage included). To purchase, contact the CHARGE Syndrome Foundation, Inc., 409 Vandiver Dr Ste 5-104, Columbia MO 65202-1563. Orders will be limited to one copy.

# RESEARCH ACCOUNT

## A REVIEW OF RESEARCH PROJECTS

Meg Hefner, M.S. Chair, Research Committee

The Research Committee has been very busy with numerous requests to review proposals. We have not had any requests for funding so far this year. Here is a status report on the research in progress:

### Already approved/in progress

**Balance:** Gina Pucci's survey was approved by the Committee and the Board. A notice about the study went in the Spring Newsletter and to the listserv on April 27. As of April 25, Gina had received about a dozen requests for participation.

**Hearing**: COMMUNCATION DEVELOPMENT IN CHARGE James Thelin, Emily Barker, Holly Beason, and Kristina Keller Department of Audiology and Speech Pathology, University of Tennessee

This project has two parts: (1)a review and synthesis of the literature on factors related to communication development, and (2) analysis of information provided by parents about communication development in their children and the unique information that they wish to share about solving communication problems. The reviews of the literature are nearly complete and the survey has been distributed by mail from the Foundation office, by email on the listserv, and by email to the members of CHARGE Syndrome Canada. About 20 responses have been received at this time.

**Growth charts**: This study started out as a Genetic Counseling thesis topic, with me (Meg) as one of the thesis advisors. The protocol was approved by the Research Committee and the Board in the fall of 2004. The student doing the study dropped out of the training program before final IRB approval was completed at University of Cincinnati. At the moment, the project is on hold. I will be transferring the project to Saint Louis University in the near future and I will be completing this project.

**Attachment and bonding in CHARGE:** Tim Hartshorne has a student interested in a follow up to an earlier study of attachment and bonding between parents and infants with CHARGE. Tim's proposal has been reviewed by the Research Committee and approved by the Board.

### Approved by others

**Natural history of CHARGE adolescents**: Tim Hartshorne has spearheaded a joint effort with me (Meg), Kim Blake (Canada), George Williams (Australia) and Jeremy Kirk (UK). Tim just received approval of his grant proposal to Central Michigan University for a pilot study looking at 30 adolescents from the US, Canada, UK and Australia. The goal of the pilot study would be to get some baseline information to help plan a large multicenter long term (NIH funded) study on CHARGE. The next step is for Tim to write the IRB proposal and have the whole project go through the CHARGE Syndrome Foundation for approval and assistance in recruiting appropriate subjects.

**Coloboma:** Brian P. Brooks, M.D., Ph.D. at the National Eye Institute & National Human Genome Research Institute at the NIH has a protocol for looking at children with colobomas, with or with out other issues. I have copies of his consent form. He has asked us to pass on his contact information to anyone interested in participating. The Research Committee and Board have not had any direct involvement in this study.

**Kim Blake:** Kim has a number of studies ongoing, but I don't know details at the moment. I know she has students working on osteoporosis and feeding, among other things. She will be presenting some of her findings in Miami. She has not requested review of any proposals or any money in the past year.

### Pending/Future possibilities

**Perkins grads:** Laurie Denno and Pam Ryan are piloting a survey of Perkins grads with CHARGE. They will inquire about living situation, vocational training, job status, social status, and so on. They sent me a preliminary version of the survey in February, which I reviewed in detail and sent back to them. As of May 9, they plan to do a small pilot with local young adults. The pilot study will be presented as a poster in Miami, with plans to do a larger study in the future.

**Sense of smell and other cranial nerves:** Dr. Marc Williams, now at University of Utah, is interested in looking at cranial nerves in CHARGE, especially sense of smell and the nerves involved in chewing. Originally, he was hoping to come to Miami to conduct some research. Unfortunately he will be unable to attend this year. But he does plan to pursue it in the future.

## The Greater Waldorf Jaycees Big 5 Dinner and Dance

On May 14th, Tommy and Robin Adkins, the Adkins Family, the Big 5 Committee, and the Greater Waldorf Jaycees held the Seventh Annual Big 5 Dinner and Dance to benefit the CHARGE Syndrome Foundation. Inc. This year's theme was the Wild West and the hall was decorated to include a jail and the CHARGE Saloon. They even were able to borrow a full size stuffed horse that the owners had never lent out prior to this event. The band played in front of the jail and the tables were decorated with cowboy hats and poker cards. There was a silent auction, 50-50, a raffle for a condo for a week in Myrtle Beach, and plenty of games to win numerous prizes.

Tommy, Robin and the Big 5 Committee presented a check to the foundation in the amount of $15,000.00. Over the past seven years the Greater Waldorf Jaycees have raised over $ 90,000.00 for the foundation.

The Board of Directors along with the members of the CHARGE Syndrome Foundation can not thank Tommy, Robin, the Adkins family, the Big 5 Committee, and all of the Greater Waldorf Jaycees enough for their continued support. They are one of the largest annual supporters of the foundation. We thank them for their continued love and dedication to our children

**! ! ! ! ! THANK YOU JAYCEES ! ! ! ! !**

## *We thank everyone for their generous support . . .*

**GENERAL CONTRIBUTIONS**
Mr. and Mrs. Earnest Neeper MD
Alan & Martha Wismer PA
Jacqueline D'Urso CA
Colleen Feather PA
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United Way Kitsap County WA
Thomas West 2003 Community Solutions Fund
Because We Care Employee Giving Campaign MN

**SPECIAL REQUESTS**
Mr. and Mrs Ray Grimes TX
*In honor of Christian Roberts' 3rd Birthday*
Alison and Brad Walter RI
*In honor of Sheri Stanger's Birthday*
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*In honor of Erika Feather*

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**Spanfelner Memorial**
*In memory of Will Spanfelner, son of Michael & Amy Spanfelner of Chico, CA*
Jim and Teresa Cottier CA
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Elizabeth Seidelhuber CA
Hanna Sue Harvey CA
Frank and Joan Spanfelner CA
The Shields Family CA

**James Barone Memorial**
*In memory of James Vincent Barone, grandson of Mrs. Jean O'Malley, NY*
Helen Guarino and Diane Buscetta NY
Victoria Pisciotta NY

**Mixon Memorial**
*In memory of Marin Rene Mixon, daughter of Ron & Rene Mixon, GA*
Toles, Temple and Wright, Inc GA
Anita and Howard Lowden GA
Lucile and Bud Martin GA
Grace Bible Study GA
Marsha and Don Black, Eleanor and Alex Sams & Jody and Julie Black and family GA

**RESEARCH**
Bob & Jeannie Scharf CA

**SCHOLARSHIP**
John and Sharon Lauger TX

# Educational and Behavioral Implications of Missing Balance Sense in CHARGE Syndrome
## by David Brown, CDBS Educational Specialist

When this condition was first named in 1981, the six diagnostic criteria that were used to make up the acronym ‘CHARGE’ were thought to be the main features of the condition, but since then over 40 associated anomalies have been identified (CHARGE Syndrome Management Manual of the CHARGE Foundation, and see http://www.widerworld.co.uk/charge/whatis.htm), which makes CHARGE, medically and developmentally, one of the most complex conditions that we know. Children with CHARGE are also likely to be amongst the most truly ‘multi sensory impaired’ people you will ever meet, having difficulties not just with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell. The many different anomalies associated with CHARGE will each impose different, varying, and often, conflicting demands upon the child. One of the most pervasive but least understood of these is the missing sense of balance.

### Balance and Low Tone

### Balance

It is thought that most people with CHARGE have no balance sense due to the malfunctioning or absence of the semicircular canals (the receptors of the balance sense) in the inner ears. The semicircular canals play a crucial role in organizing sensory inputs in all the other sensory channels, so this anomaly has a profound affect on all areas of functioning for the whole life of the child, but it’s importance and impact is usually over-looked and underplayed, especially once the child is standing and walking. In the early years the child is likely to show the following:

- very low muscle tone (“floppy muscles”)
- very poor head control and a generally poor ability to resist against gravity
- strong postural insecurity when held upright or sat on a lap
- a marked preference for laying flat on the back (supine), and later on the sides too, for long periods of time for most activities
- very delayed mobility, then unique movement patterns including shuffling backwards head-first in supine, shuffling sideways in supine, 5-point crawling (using both knees, both arms and the forehead down on the floor as an extra support)
- floor sitting with the legs in a “W” position to give a broader and more secure base
- extreme fatigue after trying to resist gravity (e.g., by sitting or holding the head erect) for short periods of time

In later childhood and adolescence the problems with fatigue, postural control, and sitting or standing unsupported will be less evident but still present. Sometimes the student will benefit from using an adapted chair, with arms and a footrest, possibly also with a tilted seat to encourage more active sitting. There may still be a great need to rest the head on one or both arms or even down on the desktop itself, in order to read or write. Some older children and teenagers can seem to function quite well at their desk for extended periods of time, but they then need periodically to get into a horizontal position to relax and to re-charge their energy levels for the next exertions. They may also need these periods in the horizontal position to reorganize their sensory system using behaviors like leg kicking, arm waving, hyperventilating, or gazing at bright light. Extended periods of standing still and entirely unsupported are usually particularly challenging. Regular input from a physical therapist is very important for all children with CHARGE, but the therapists will need to be informed about the high frequency of severe balance problems in this population and about the implications of this.

### Low Muscle Tone

Very low muscle tone is partly an outcome of severe balance problems, but is also associated with low vision, breathing difficulties, and generally reduced sensory inputs hence reduced perceptual awareness, and the problem is then compounded by the lack of motivation to move and the resulting lack of “exercise”. Saving reactions, standing, cruising, and independent walking usually develop very late (one British survey found a mean age of 4 years for independent walking). When children do walk there is often a characteristic gait, some aspects of which may remain evident for many years—feet spaced widely apart, knees bent, body rolling from side to side with each step, feet sliding along the floor or being planted down very firmly on the floor (maybe several times, almost like patting the floor with the foot) with each step, arms held up like a tightrope walker. Some children walk with repeating swaying circular movements of the upper body and head, as if trying to keep some awareness of the danger areas at the parameters of safe posture. On-going monitoring by a Physical Therapist is important because there is a high risk of the development of scoliosis (curvature of the spine) in later childhood and the teenage years: this may then require therapy treatment and environmental adaptations, the wearing of a body brace, or even spinal surgery in acute cases.

### Equilibrium

Postural security and a good sense of equilibrium depend upon the effective development and functioning of three different but interdependent sensory systems (known as the 'Equilibrium Triad')—these are the vision sense, the balance sense, and the tactile/proprioceptive senses. In people with CHARGE all of these sensory systems are likely to be missing or impaired in some way, which explains the slow development of large motor skills and mobility, but also makes it remarkable that the majority of children with CHARGE do eventually stand up and walk. Any input that helps to improve the functioning of any of the senses in this Equilibrium Triad can, therefore, be regarded as making a contribution to the development of independent standing and walking.

### Balance and Vision

There are strong links between the balance sense and vision, and problems with balance may affect the ability to maintain a stable visual field, to follow moving objects smoothly with the eyes, and to differentiate whether it is the object or oneself that is moving. Some children may appear to be totally blind if their postural security is challenged, but may show some well-developed visual (and other) skills once they are flat on their back or side on a stable surface. As they get older children may use residual vision to help them to stay upright, compensating for having no balance sense by using the strong visual impressions made by horizontal and vertical lines in a room (e.g., walls and the edges of windows, doors, table tops, and wall-mounted pictures); they may have much less equilibrium outdoors where these strong visual markers are largely absent. One result might be a reluctance to go outdoors (e.g., during recess at school), and another might be an inability to perform certain tasks outdoors (e.g., playing soccer) that are carried out very well indoors. For children who are reading, the use of a typoscope (a letter-box shaped frame) can help by isolating one single line of text at a time.

### Balance and Hearing

Several writers have emphasized the links that exist between the balance sense and the ability to process sound and to develop spoken language. This has obvious implications for people with CHARGE, and a collaborative approach that brings together a teacher of the Deaf and hard of hearing, a speech therapist, and an occupational therapist trained in sensory integration therapy (or any combination of these) should be very helpful.

## Sensory Integration Dysfunction

This problem is inherent in CHARGE, and significant difficulties caused by poorly modulated sensory systems are very common. Many behaviors, some of them apparently contradictory, could indicate the need for a sensory integration (SI) assessment by a trained occupational therapist:

- rejection of textures in the mouth apart from pureed food but mouthing of all kinds of non-food items (e.g., stones, wood, cloth, soil)
- inability to chew and bite on solid foods but excessive biting and chewing on non-food items/persistent teeth grinding
- rejection of certain tactile inputs as if they are painful but apparent non-awareness of certain other tactile inputs (which for us might be painful!)
- extreme postural insecurity when sat or stood by another person but pleasurable responses to strong rhythmic movement experiences (e.g., rocking, bouncing, swinging) • periods of frantic over-activity but also sudden periods of apparent 'burn-out'
- abnormally high pain thresholds
- very delayed awareness of bowel and bladder movements
- disturbed and inconsistent sleep patterns
- behaviors that seek and provide very strong sensory inputs, e.g., self-biting or scratching, skin picking, spinning, rocking, bouncing, shoulder shrugging, leg swinging, hand flapping, self-slapping, as a way of getting the body reorganized

Some typical techniques suggested by a therapist following SI assessment might include brushing protocols, rhythmic joint compression, deep tissue massage, vibrotactile input, a range of large movement activities, and the use of weighted clothing. A variety of outcomes might be anticipated from implementing these techniques, including improving the child's ability to attend to sensory information in the environment, improving muscle tone, improving awareness and tolerance of touch, improving attention span and decreasing distractibility, reducing the need for self-injurious behavior, improving sleep patterns, and generally increasing the child's ability to remain both alert and calm in stressful situations. This kind of SI perspective might be needed, regularly or periodically, throughout the child's life and should never be automatically regarded as a one-time 'fix'. I believe that every person with CHARGE would benefit significantly from having at least intermittent SI assessment by a suitably qualified occupational therapist.

There must be all sorts of different reasons why children with CHARGE perseverate, but I think it may often be a technique that they use to establish a firm physical, emotional, perceptual, and cognitive 'base' each time before they move on into comparatively uncharted territory. Successful teaching often depends on allowing for this need and spending some time alerting the child to the fact that you are there, who you are, what you are going to be doing together, how it will be done, and so on. The child may need considerable time, and help, to establish a secure and stable physical base as a first priority in every interaction.

## In Conclusion

Teamwork - this is all much more complicated than we will ever truly realize, and many disciplines and viewpoints will need to be discussed and considered if appropriate programs are to be created and maintained.

Priorities — with such complexity it is always difficult to decide on the best priorities from moment to moment, day to day, and week to week. Often, established low vision, or hearing impaired, or physical therapy (or whatever) priorities may have to be put to one side so that the emphasis can go on to other things. Great creativity will be needed to ensure that the educational program is flexible and alert to the needs of the moment, but also has the balance needed to address all the many and complex needs of the child as effectively as possible.

One thing at a time — only the clearest view and the strongest empathy will help people to gain any insight into what an activity really means for the child. "What am I trying to do at this moment/in this activity?" is always a good question to have in our minds, but a more urgent question might be "What is the child's perception of what I am trying to do at this moment/in this activity?" In other words, what are likely to be the main demands upon the child's attention as a result of the way I have organized this session?

Behavior - parents and professionals often report themselves puzzled, confused, and frustrated by the behavior patterns of children with CHARGE, and there is no doubt that these children can be particularly challenging people with whom to work and, especially, to live. There has been a long-standing debate about "CHARGE behavior" amongst families with children with CHARGE, and recently some research into behavior has been begun in the US, in the UK, and in France. I hope that some of the information and thoughts in this paper will help people to develop their own insights into why certain things happen the way that they do. Above all, I hope this paper will remind people of the immense difficulties these children face in almost everything that they do, and, as a consequence, of the very high levels of stress with which they must live for much or even all of their lives. Time spent trying to reduce stress levels, and trying to give the children acceptable strategies for doing this for themselves, must be one of the most precious gifts we can offer them, and one of the biggest favors we can do ourselves as educators.

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Ed. Note: David Brown will be the Keynote Speaker on Sunday morning at our conference. He also will be a presenter at one of the breakout sessions.

# CONFERENCE ACCOUNT

## 2005 AUCTION NEEDS DONATIONS . . .

As previously announced, this year's conference will once again feature a silent auction fundraiser to help meet the general expenses of the Foundation. Our goal is to raise $10,000. This year the donation of auction items has been slower than in the past, perhaps because so many companies are watching their expenses more closely. Therefore, WE NEED YOUR HELP to make this a success! Please contact your friends, family members, and companies that you do business with to solicit donated items for the auction. A solicitation letter and a donor form are available from the Foundation office, or on-line at our website. Thanks for your support.

Dennis O'Toole, Silent Auction Chair, dennis@chargesyndrome.org or 440-331-4869

## MEMBERSHIP MEETING

On Saturday morning at the conference, we will have a membership meeting. On the agenda are a presentation by the committee chairs, awards and special recognitions, and a brief business meeting. Members will be asked to vote on the following amendment to the Foundation's Bylaws. (Copies of the CHARGE Syndrome Foundation Bylaws are available upon request.) The Board of Directors is recommending that the current Article XVI be replaced by the proposed Article XVI.

### CURRENT BYLAWS:
### ARTICLE XVI AMENDMENT OF BYLAWS

Section 1. The Board of Directors shall recommend to the membership any bylaws changes prior to the biennial meeting. Final approval to amend or rescind these bylaws requires a 2/3 vote of those members present and voting.

Section 2. The Secretary shall send notice of proposed changes or amendments to these bylaws to each member of the Foundation at least thirty (30) days prior to meeting at which they are to be voted.

### PROPOSED BYLAWS:
### ARTICLE XVI AMENDMENT OF BYLAWS

Section 1. The Board of Directors may recommend amendment, repeal or enactment of new Bylaws by an affirmative vote of two-thirds (2/3) of the Board at any regular or special meeting.

Section 2. Upon recommendation by the Board of Directors, the proposed amendments shall be submitted to the membership for approval. The proposed amendments and ballot shall be mailed (via first class mail or electronic mail) to all members in good standing. Amendments may be enacted by the affirmative vote of two-thirds (2/3) of the members voting.

## 2005 Calendar

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| **June 26** | **Hotel Reservation Deadline** |
| **June 30** | **Registration Deadline** |
| **July 17-23** | **CHARGE Syndrome Awareness Week** |
| **July 22-24** | **7th International CHARGE Syndrome Conference, Miami Beach, Florida** |
| **September 1** | **Deadline for items for the Fall Issue of CHARGE Accounts (Conference Wrap-Up)** |